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Seizure and Sudden Unexpected Death in Epilepsy (SUDEP) characteristics in an urban UK intellectual disability service

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Running title:

Seizures, SUDEP & ID

Highlights

- Service evaluation of intellectual disability (ID), epilepsy & SUDEP risk factors
-
- Examines holistic care in a non-epilepsy managing UK urban community ID service
- 20% in the ID cohort had seizures consistent with expected 22.5% prevalence
- Significant multi-morbidity, polypharmacy, SUDEP risk & lack of care plans found
- Person centred risk communication & care plans are easily achievable & essential

ABSTRACT

Purpose: This study identifies epilepsy related characteristics and SUDEP risk factors in people with epilepsy (PWE) open to an urban community ID service in the UK where managing epilepsy is not part of the service remit, to understand the holistic care provided to this vulnerable population.

Methods: Electronic record database search in a north London community ID service (catchment population approx. 290,000) identified relevant ID/epilepsy characteristics in PWE to compare those with mild ID to moderate-profound ID. Patients, their families/carers were administered the SUDEP and Seizure Safety Checklist ("Checklist"). Risk management comparison was made to similar data from Cornwall UK where PWE are supported within the ID service and the Checklist used annually.

Results: Fifth (137/697) of people open to the service, had epilepsy. Over 3/4 had moderate-profound ID. Neurodevelopmental disorders were coexistent in 2/3, psychiatric conditions in 1/3 of which 1/4 had psychosis. Mean number of anti-seizure drugs was 1.45 ± 0.98 with 1/4 on psychotropics. Over a third did not have an epilepsy care plan. None contacted (n =103) had SUDEP awareness. Median Checklist risk factors were seven (IQR 4.5 - 9). A third had experienced seizures lasting >5 mins or status epilepticus. In comparison to the Cornish ID data significant differences were evident in four of seven modifiable risk factors.

Conclusions: This real world study highlights complexity and risks of PWE and ID. A lack of "joined up" approach can undermine this vulnerable population safety. Person centred risk communication and care plans are easily achievable and essential.

Keywords:

SUDEP; seizure characteristics**;** Communication**;** Intellectual Disability; neurodevelopment; Seizure safety & SUDEP Checklist; service delivery

INTRODUCTION

Intellectual disability (ID) is defined as a significant impairment of intellectual function and adaptive behaviour, developing before 18 years of age[1]. People with ID have higher rates of morbidity and mortality than those without ID[2,3]. The reasons for this are multifactorial and range from higher prevalence of co-morbidity to barriers accessing suitable services[4,5].

Epidemiological studies suggest that 20-25% people with ID have epilepsy[6] compared to 0.5-1% in the general population[7]. There is a positive correlation between increasing ID severity and seizure prevelance[8].

The recent national enquiry into premature mortality in people with ID has shown that people with ID can die up to 25 years earlier than the general population. A major direct and contributory cause is epilepsy. Five percent of people died as a direct result of seizures and seizures were an associated condition in 45% of all premature deaths[9]. Sudden Unexpected Death in Epilepsy (SUDEP) is considered to be three to nine-fold higher in ID than general populations[10].

People with ID and epilepsy are associated with higher levels of mental illness, neurodevelopmental conditions co-morbidity and irrational polypharmacy[11].The management of epilepsy in adults with ID is therefore complex and there is a paucity of research or real world evidence of the nature and degree of clinical complexity, drug prescribing, risk assessments and patterns of care of people with ID and epilepsy as compared to general population[4,5,12].

Aim: -

1. To identify and characterise, current standards of care, prescribing and risk assessments in an urban cohort of people with ID and epilepsy

2. To inform if there is a difference in the above characteristics between those with mild ID to moderate to profound ID

METHODS

The STROBE checklist (supporting file) was used to guide the cross sectional study. This study was conducted between May – June 2019 in a community ID service comprising multidisciplinary professionals: psychiatrists, psychologists, social workers, speech and language therapists, occupational therapists and ID nurses as a quality improvement project to improve care for people with ID and Epilepsy open to services. The population served is an inner London borough covering a catchment population of approximately 290,000. In this area, epilepsy management is largely in primary care with access to secondary and quaternary neurology services at local hospitals depending on general practitioner (GP) referral. The study was registered with the local NHS Trust audit department (registration number: 256855). The NHS Health research authority tool (http://www.hra-decisiontools.org.uk/research/index.html) was used to confirm that no ethics is needed for this project (Supplementary File 1). The project was co-designed with SUDEP Action, Patient and Public Involvement lead for the project.

A search of the electronic record database (Mosaic, Servelec) of the ID specialist service using the terms: “epilepsy”, “seizure” was conducted. The database had people presently open to the ID service. All patients aged 18 or older with an ID identified by the search were included.

By case note review, individual data:

1. Demographics (age, gender)
2. Level of ID – this was divided as per the ICD criteria[1] into 2 groups: mild ID and ‘moderate-profound ID based on the rationale in Appendix 1.

By descriptive statistics, compilation data:

3. Number of those experiencing mental or behavioural disorders, genetic disorders, and neurodevelopmental disorders (ASD, ADHD) according to ICD/DSM diagnosis.
4. Number prescribed psychotropic medication (anti-psychotic and non-anti-psychotic). The British National Formulary (BNF) was used to define the category of the specific nature of the drug[13].

The SUDEP and Seizure Safety Checklist ("Checklist" - managed by SUDEP Action & available via https://www.sudep.org/checklist) is a validated structured tool which outlines risk factors both modifiable and non-modifiable which increase the risk of SUDEP and undermine seizure safety[14]. Tool description is provided in Supplementary File 2. Each PWE, their families/carers were contacted by telephone to discuss and record risk factors using the SUDEP and Seizure Safety Checklist (Table 1). Each contact was asked whether the PWE had an epilepsy care plan.

Contact was made only with those who were open to the clinicians of the specialist service and being regularly reviewed for ID related needs. As NICE since 2003 and all good practice national and international epilepsy guidance has advocated that SUDEP and epilepsy related risk issues be discussed for any PWE, the expectation was that the population contacted would be SUDEP aware. The discussion on SUDEP was done to elicit person centred understanding of risk as part of their clinical support. The guidance provided by the Royal College of Psychiatrists in how to have a sensitive conversation around epilepsy risk and SUDEP was followed[4]. A trainee psychiatrist contacted all the eligible PWE (i.e. those open to the service) as part of a planned clinical review. He discussed their current well-being and ongoing health needs and on the matter of seizures offered to discuss specific person centred factors of seizure risks. The discussion was facilitated by the Checklist. SUDEP was explained in the context of the discussion. On completion feedback was given and interviewees asked if they had discussion specifically about SUDEP or epilepsy risk

anytime post diagnosis of seizures. Further inquiry was made if SUDEP or epilepsy risk was mentioned or remembered irrespective of lack of specifics. Interviewees were asked to again contact the services if they felt anxious or confused about the conversation and discussion had.

Comparison of the risk factors was undertaken with similar data from Cornwall UK. There a clinic specialized in epilepsy and intellectual disability (ID) has had discussion of SUDEP and seizure risk as part of routine practice since 2010. The administration of the Checklist happens annually. The Checklist was administered by an epilepsy nurse or by a specialist who had training in doing so. The Checklist data set is registered as part of an ongoing rolling audit to inform on service outcomes. The last available checklist data set was used.

Statistical analysis

Data are presented descriptively in the form of summary measures by cohort (and total sample population). The binary risk factors are summarized as relative frequencies and the total risk score by the median and interquartile range. Pearson's Chi Squared test with p-values computed by Monte Carlo simulation was used to explore associations between the level of ID and the clinical factors. Comparison was made between those with mild ID and those with moderate to profound ID for all domains. Bonferroni adjustment was performed to address multiple testing. The threshold set for statistical significance was $p = 0.0025$.

Further comparisons of risk factor prevalence between the study cohort and a previous cohort from Cornwall UK were conducted using the Chi Squared test with simulated p-values to inform discussion. No baseline comparison between these two populations (London and Cornwall) was done at the start of the project.

RESULTS

137 out of 697 (20%) adults with ID open to the service had a diagnosis of epilepsy as identified by the search. None were under the review of the service for epilepsy. Data was obtained from 103 (75%) of those identified. Patients' age was 39 ± 12.5 and gender ratio

was 1.86: 1 (male: female). 24 (1:67: 1) had mild ID and 79 (1.93: 1) had moderate-profound ID. There were co-existent neurodevelopmental disorders (autism, ADHD) in 71 (2.55: 1). 34 (1.83: 1) had some form of co-existent mental disorder and 16 (1.29: 1) had a genetic disorder.

Eighty-five out of 103 patients (83%) experienced generalised tonic clonic seizures (GTCS), seven (7%) had focal seizures, 11 (11%) had unknown seizure phenotype. Forty-nine had a GTCS in the last year. Forty-six (45%) had a seizure in the last six months. 11 (11%) reported having a seizure more than once a month and 21 (20%) had a seizure more than once a week. In this cohort, patients were on a mean number of 1.45 ± 0.98 anti-epileptic drugs (AEDs), 23 (22%) were on antipsychotics and 11 (10%) on other psychotropics. 26 (25%) patients had AED compliance issues. Only 61 (59%) of patients had an epilepsy care plan. A third had previously met the definition for status epilepticus[15].

Co-existing mental health problems was more likely associated with mild ID (n= 14, 58%). Nearly 25% (n =6) of this subset had seizures more than once a month and AED compliance issues. Only 15 (44%) had an epilepsy care plan.

In those with a neurodevelopmental disorder, 16 (22%) had a seizure more than once a month and 14 (20%) had a seizure more than once a week. Eight (11%) had an issue of AED compliance. 41 (58%) had an epilepsy care plan. Of specific interest is that those with neurodevelopmental co-morbidity were more likely to experience higher frequency of seizures monthly than those without (42% vs. 31%).

SUDEP and Seizure Risk Factors

None of the 103 people who agreed to be contacted were neither aware of SUDEP nor the risks for SUDEP. The median total number of risk factors was 7 (IQR 5 – 9). There was a median of 5 (IQR 4 – 5) non-modifiable risk factors and 3 (IQR 1 – 4.5) modifiable risk factors in this cohort. There was no significant difference between mild ID to moderate to

profound ID groups for total, modifiable or non-modifiable factors (Table 2/Figure 1). Likewise, no significant difference existed on risk factors when those with neurodevelopmental disorders were compared with those without (Figure 2). Over 90% of patients had at least 1 modifiable risk factor for seizures and SUDEP (Table 3).

46 (45%) of patients reported nocturnal seizures, of those 10 (22%) did not have any nocturnal surveillance. Those who did have seizure surveillance at night, had audio-visual monitoring (n =18), physical checks (n = 9) or other monitoring modalities (n = 9).

No contact at the end of the interview told of any distress or anxiety from the discussion. No calls for further information, clarification or distress, were received post discussion either to SUDEP Action who provide a helpline support or to the clinical service.

Cornwall Data –

The Cornish ID sample (n =129) was drawn from approximately 300,000 catchment population. The up to date (till 2018) SUDEP and Seizure Checklist data of all eligible 129 PWE and ID of a total of 169 PWE open to the service was used. All PWE had at least two Checklist reviews on file. When contact had been made to update the Checklist with the 129 PWE and/or their carers inquiries had been made of preliminary awareness and risks of SUDEP including recollection of the previous discussion. All 129 PWE and/or their carers were SUDEP aware. There were 75 males (58%) and 54 females (42%).Mean age was 37 (SD: 14). Duration of epilepsy was greater than 15 years for 117 PWE (91%) with three (2%) having had seizures for 10-15 years, one for 5-10 years and seven (5%) for less than five years. Generalised seizures were present in 87 (68%). Mean AEDs in this cohort was 2.2 ± 1. Compliance concerns were present in 14 people (11%) while one person had a reported alcohol problem.

A brief comparison was made to findings of using the Checklist in the two cohorts (Table 4). While no differences were found in the non-modifiable factors, significant differences existed in numerous modifiable factors. The Cornwall cohort had lesser use of emergency services

(p<0.001), less seizures lasting more than 5 min/Status Epilepticus (p =0.002), more presence of surveillance at night (p =0.02), and lesser presence of concurrent psychiatric disorder (p<0.001) than the London cohort.

DISCUSSION

This small real-world study characterises the seizure profiles and risk factors for SUDEP of people open to an urban integrated ID service in an inner borough of London. The service is led by psychiatrists with no commissioned role or remit for epilepsy. In this area, there are secondary and quaternary neurology services; however there is no integrated epilepsy care. This model is consistent with many other urban areas in the UK[16].

The prevalence of epilepsy in this study was concordant with previous studies at 20%[8]. The findings that a third of people had a major mental health condition, more than two thirds neurodevelopmental disorders (ASD and ADHD), high proportions of genetic disorders and prescribing of anti-seizure drug and psychotropic polypharmacy is consistent with other studies and reports[4,5]. The study again highlights that polypharmacy, particularly the drug burden of AEDs and psychotropics is a developing issue of concern in this vulnerable population and attempts need to be made to consider active deprescribing to reduce the burden of iatrogenic harm[17,18,].

Those with co-morbidity such as a neurodevelopmental condition had higher health burden particularly more seizure frequency. Of concern, is that the whole cohort had ongoing seizure activity thus highlighting the high burden of risk. Inspite of this and the added outlined health complexities nearly two thirds did not have a basic epilepsy care plan.

None of those contacted (n =103) knew of SUDEP or recalled any clinician discussing this with them. Due to the lack of an integrated neurology service it was not possible to verify if there had been documented discussion about SUDEP. However, even if there had been

such a discussion, it is clear that there is no recall. This reiterates the developing evidence for having person centred risk discussions regularly[19-220].

More than 60% of this cohort had a modifiable risk factor. In particular, the presence of high risk SUDEP factors such as nocturnal seizures (53%) and lack of surveillance at night (27%) in a significant number of people was a concern. Recent evidence is suggestive of nocturnal seizures and the type of supervision being an increased SUDEP risk for people with ID[23].

There is evidence that regular communication of SUDEP and seizure risk improves seizure related outcomes including in people with ID[24]. The Cornish sample had been receiving regular risk information periodically for over five years. While the burden of non-modifiable risk between the two populations was similar there were significant differences in important modifiable risk factors such as episodes of status, nocturnal surveillance, psychiatric disorders and the use of emergency services. This could indicate that regular communication of risk change is associated with mitigation of modifiable risk factors.

This pragmatic real-world study is not without limitations. This was a cross-sectional explorative study looking at real world practice. The study lacks definitive comparable samples, there is a lack of definitive seizure details, no seizure outcome data, no historical data on drug use and no attempt has been made to validate psychiatric diagnosis. The level of seizure control has not been looked and could be a possible confounder to the prescribing. Further limitations include the study being retrospective, involving data collection from clinical records, clinician attributes and practice standards. Limitations in diagnosis and classification have been minimised by using consistent recognised diagnostic standards and rationale (Appendix 1)

CONCLUSION

Increasingly, there is recognition that people with ID and epilepsy are a marginalized vulnerable group. However, few studies exist which quantify the problem. This is one of the first studies in the UK to do so in an urban cohort. We looked at a population of people with

ID and epilepsy to describe their characteristics and management issues. Our results contrast with what we would expect for epilepsy in the general population. The findings suggest that while the epilepsy needs of people with ID is significant there is a need to consider role of treatment resistance, multimorbidity and polypharmacy and in particular issues of risk communication as evidenced by this study.

Particular attention should be given to eliciting the history of nocturnal seizures which increase risk significantly of SUDEP and stress the importance of nocturnal monitoring particularly use of suitable audio or video monitors[25, 26]. While the evidence to support nocturnal monitoring to mitigate SUDEP risk is developing and needs to be balanced on the potential of invading an individual's privacy it needs to be weighed in best interest to that many people with ID could struggle to understand and communicate any events which occur to them at night thus requiring a higher level of attention and surveillance to mitigate the harm risk.

Interestingly, providing and reviewing basic risk communication regularly and ensuring suitable care plans which do not require any major epilepsy specialism or resource can significantly improve care and safety.

However, to deal with the more complex issues of multi-morbidity and polypharmacy a concerted multidisciplinary approach with a holistic view on quality of life and safety might be needed to provide more satisfactory individually centred outcomes.

Disclosures:

No known conflict of interest for JS, BP, WH. SA is the deputy chief executive of SUDEP Action and charity lead of the SUDEP and Seizure Checklist/EpSMon project. RS has received institutional and research support and/or personal fees from LivaNova, UCB, Eisai, Special Products, Bial and Desitin outside the submitted work. He is the medical lead of the ad of the SUDEP and Seizure Checklist/EpSMon project. It is free to download and use. The Checklist is used in the current project.

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Conflict of interest

No known conflict of interest exists for any of the authors involved in this manuscript.

Appendix 1: Rationale for examining the mild and moderate- profound ID as two groups:

1. Epilepsy possibly due to disturbed brain function is present in 30 - 50% of the moderate to profound ID group as compared to 8-12% in the mild ID population and 0.6 -1% in general population[27 -29].

2. Moderate to profound ID have a low prevalence and together they would combine to form 15% of the total ID population[30]. Taken individually it would be difficult to achieve satisfactory power to deliver meaningful conclusions.

3. Moderate to profound ID is difficult to assess and classify which causes significant issues with accuracy of specific diagnosis of severe or profound ID.

REFERENCES

1. Organization WH. ICD-10 : international statistical classification of diseases and related health problems : tenth revision, 2nd ed. In:2004.
2. Heslop P, Blair P, Fleming P, Hoghton M, Marriott A, Russ L. *Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) Final report.* 2013.
3. Emerson E, Hatton C, Baines S, Robertson J. The physical health of British adults with intellectual disability: cross sectional study. *International journal for equity in health.* 2016;15:11-11.
4. Psychiatrists RCo. Management of epilepsy in adults with intellectual disability. In. *College Report CR 203*2017.
5. Psychiatrists RCo. Prescribing anti-epileptic drugs for people with epilepsy and intellectual disability. In. *College Report CR 206*2017.
6. Lhatoo SD, Sander JWAS. The Epidemiology of Epilepsy and Learning Disability. *Epilepsia.* 2001;42(s1):6-9.
7. Sander JW, Shorvon SD. Epidemiology of the epilepsies. *Journal of Neurology, Neurosurgery & Psychiatry.* 1996;61(5):433.
8. Robertson J, Hatton C, Emerson E, Baines S. Prevalence of epilepsy among people with intellectual disabilities: A systematic review. *Seizure.* 2015;29:46-62.
9. Programme TLDMRL. Annual Report 2018. In: University of Bristol Norah Fry Centre for Disability Studies; 2019.
10. Young C, Shankar R, Palmer J, et al. Does intellectual disability increase sudden unexpected death in epilepsy (SUDEP) risk? *Seizure.* 2015;25:112-116.

11. Hara H. Autism and epilepsy: a retrospective follow-up study. *Brain & development.* 2007;29(8):486-490.
12. Doran Z, Shankar R, Keezer MR, et al. Managing anti-epileptic drug treatment in adult patients with intellectual disability: a serious conundrum. *European Journal of Neurology.* 2016;23(7):1152-1157.
13. Committee JF. British National Formulary 78 ed. In. London: BMJ Group and Pharmaceutical Press; 2019.
14. Shankar R, Ashby S, McLean B, Newman C. Bridging the gap of risk communication and management using the SUDEP and Seizure Safety Checklist. *Epilepsy & Behavior.* 2020;103:106419.
15. Trinka E, Cock H, Hesdorffer D, et al. A definition and classification of status epilepticus--Report of the ILAE Task Force on Classification of Status Epilepticus. *Epilepsia.* 2015;56(10):1515-1523.
16. Lines G, Henley W, Winterhalder R, Shankar R. Awareness, attitudes, skills and training needs of psychiatrists working with adults with intellectual disability in managing epilepsy. *Seizure - European Journal of Epilepsy.* 2018;63:105-112.
17. O'Dwyer M, McCallion P, McCarron M, et al. . Medication use and potentially inappropriate prescribing in older adults with intellectual disabilities: a neglected area of research. Ther Adv Drug Saf 2018;9:535–57
18. Shankar, R, Wilcock, M, Deb, S, et al. A structured programme to withdraw antipsychotics among adults with intellectual disabilities: The Cornwall experience. *J Appl Res Intellect Disabil*. 2019; 32: 1389– 1400.
19. Young C, Shankar R, Henley W, Rose A, Cheatle K, Sander JW. SUDEP and seizure safety communication: Assessing if people hear and act. *Epilepsy & behavior : E&B.* 2018;86:200-203.
20. Watkins L, Shankar R, Sander JW. Identifying and mitigating Sudden Unexpected Death in Epilepsy (SUDEP) risk factors. *Expert review of neurotherapeutics.* 2018;18(4):265-274.
21. Watkins L, Shankar R. Reducing the Risk of Sudden Unexpected Death in Epilepsy (SUDEP). *Current Treatment Options in Neurology.* 2018;20(10):40.
22. Shankar R, Newman C, Gales A, et al. Has the Time Come to Stratify and Score SUDEP Risk to Inform People With Epilepsy of Their Changes in Safety? *Frontiers in Neurology.* 2018;9(281).
23. Van der Lende M, Hesdorffer D, Sander JW, Thijs R Nocturnal supervision and SUDEP risk at different epilepsy care settings Neurology Oct 2018, 91 (16) e1508-e1518
24. Shankar R, Henley W, Boland C, et al. Decreasing the risk of sudden unexpected death in epilepsy: structured communication of risk factors for premature mortality in people with epilepsy. *European journal of neurology.* 2018;25(9):1121-1127.
25. Maguire MJ, Jackson CF, Marson AG, Nevitt SJ. Treatments for the prevention of Sudden Unexpected Death in Epilepsy (SUDEP). Cochrane Database of Systematic Reviews 2020, Issue 4. Art. No.: CD011792. DOI: 10.1002/14651858.CD011792.pub3
26. Young C, Shankar R, Henley W, Rose A, Cheatle K, Sander JW. SUDEP and seizure safety communication:Assessing if people hear and act. Epilepsy Behav. 2018;86:200–203.
27. Forsgren L, Beghi E, Oun A, Sillanpää M. The epidemiology of epilepsy in Europe - a systematic review. *Eur J Neurol.* 2005;12(4):245-253.
28. Ngugi AK, Bottomley C, Kleinschmidt I, Sander JW, Newton CR. Estimation of the burden of active and life-time epilepsy: a meta-analytic approach. *Epilepsia.* 2010;51(5):883-890.
29. Linehan C, Kerr MP, Walsh PN, et al. Examining the prevalence of epilepsy and delivery of epilepsy care in Ireland. *Epilepsia.* 2010;51(5):845-852.
30. King B, Toth K, Hodapp RM, Dykens E. Intellectual disability. *Comprehensive textbook of psychiatry.* 2009:3444-3474.

Table 1 – SUDEP and Seizure Safety Checklist (adapted from https://sudep.org/checklist)

Modifiable risk factor	**Non-modifiable risk factor**
Lack of clinical review of epilepsy in last 12 months	Early onset of epilepsy (<16 years old)
Active seizures: seizures in last 12 months	Duration of epilepsy (>15 years)
Convulsive seizures: generalised tonic clonic seizures in 12 months	Young age (20-40 years old)
Uncontrolled seizures (had seizures lasting >5 mins/status epilepticus)	Male sex
Seizure frequency	Intellectual Disability
Nocturnal seizures	
Lack of night surveillance	
Sleeping in prone position	
Anti-epileptic drug compliance issues	
Frequent anti-epileptic drug changes	
Alcohol/drug misuse	
Psychiatric disorder	
Used A&E for seizures or called 999	

Table 2 – Distribution of risk factors by ID severity

Risk factor	ID severity				
	Mild (N=24)		Moderate to profound (N=79)		
	n	%	n	%	p-value*
Epilepsy > 15 yr	20	83	66	87	0.74
Dx aged < 16 yrs	20	91	61	85	0.52
Current age 20-40 yrs	15	63	48	61	1.00
Male sex	15	63	50	63	1.00
ID present	24	100	79	100	1.00
Childbearing age and received preconception counselling	4	44	4	13	0.05
Used A&E/999	11	48	39	50	1.00
Review in last 12 months	13	54	47	59	0.81
Seizure in last year	11	46	45	57	0.37
GTCS in last year	7	29	28	35	0.63
Seizures >5 min/status epilepticus	7	30	29	37	0.63
Nocturnal seizures	8	44	38	55	0.45

Surveillance at night	7	54	31	67	0.50
Prone position	0	0	5	13	0.58
Difficulty with compliance	6	26	5	7	0.02
Frequent AED changes	3	13	4	5	0.36
Psychiatric disorder	14	58	21	27	0.007
Abuse alcohol	2	8	1	1	0.13
Take recreational drugs	1	4	1	1	0.43
Review booked	12	50	45	57	0.62

*Bonferroni threshold for statistical significance is p=0.0025

Potentially modifiable risk factors

Non-modifiable risk factors

Table 3 - Prevalence of modifiable v non-modifiable risk factors by ID severity

Risk factor grouping	ID severity				
	Mild (N=24)		Moderate to profound (N=79)		
	n	%	n	%	p-value
Modifiable	24	100	70	89	0.11
Non-modifiable*	23	96	77	97	1.00

*excluding ID

Table 4 – Comparison of Risk Factor Prevalence between London and Cornwall

Risk factor	Population				
	London (N=103)		Cornwall (N=130)		P value
	n	%	n	%	
Non-Modifiable Risk Factors					
Epilepsy lasting over 15 years	86	86%	117	91%	0.20
Diagnosed before age of 16 years	81	86%	115	89%	0.54
Current age being between 20-40 years	63	61%	64	50%	0.08
Male sex	65	63%	75	58%	0.50
Modifiable Risk Factors					
Used Emergency services i.e. Paramedics/ED in last year	50	50%	18	14%	**<0.001**
Seizures lasting more than 5 min/status epilepticus	36	35%	22	17%	**0.002**
surveillance at night	38	64%	101	81%	**0.02**
Difficulty with compliance	11	11%	14	11%	1.00
Frequent AED changes	7	7%	9	7%	1.00
concurrent psychiatric disorder	35	34%	13	10%	**<0.001**
Recognised Alcohol Abuse	3	3%	1	1%	0.32

Figure 1 – Box and whisker plots of total number of risk factors by ID severity

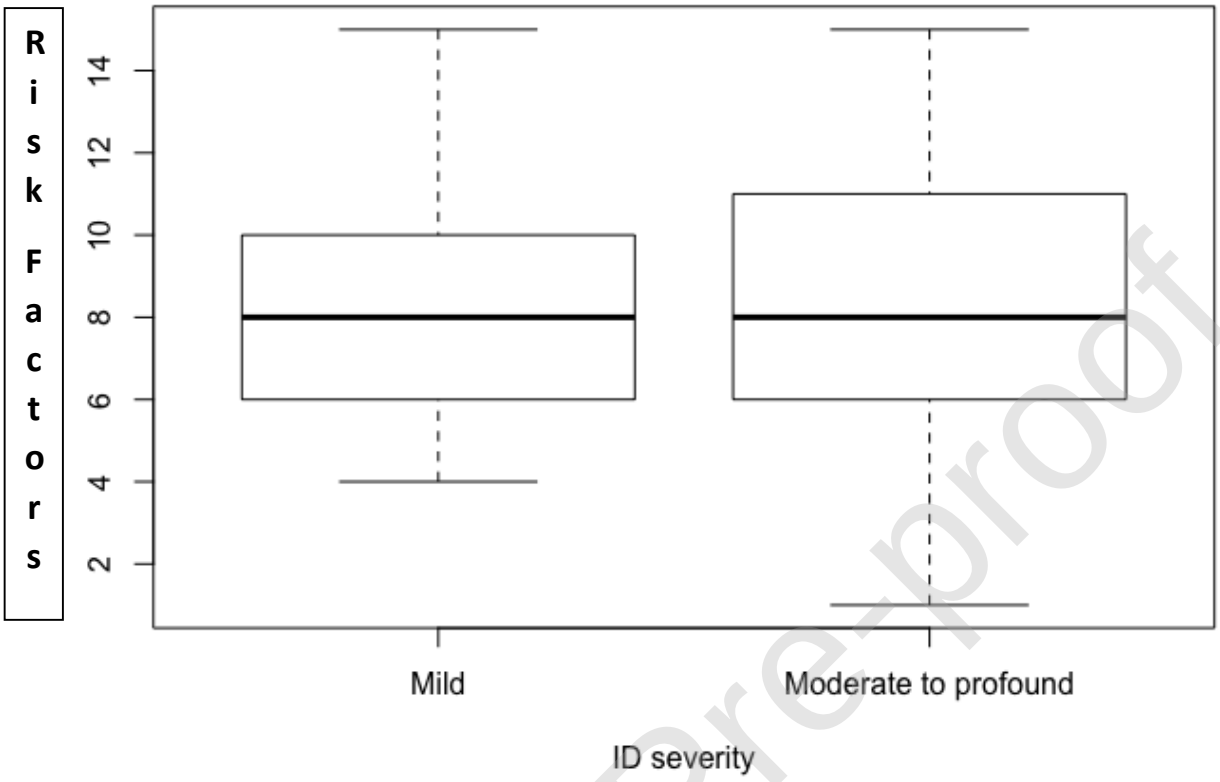

Figure 2 – Box and whisker plots of total number of risk factors by presence of neurodevelopmental disorder